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Conference or Workshop Item

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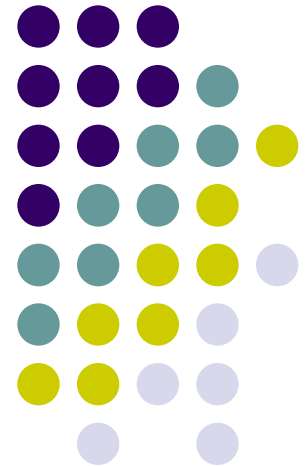
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Respite care ('short breaks') for families that include young people on the autism spectrum

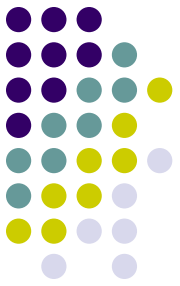
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Northamptonshire County Council

UNIVERSITY OF
BIRMINGHAM

acer Autism Centre for
Education and Research



Focus of presentation

- Overview of respite care ('short breaks')
- Why specialist services for autism?
- What works in respite care for families that include young people on the autism spectrum?

Northamptonshire



- County in centre of England
- Population – 650,000
- Northampton – 200,000
- Child population – 100,000
- Child population with ASD – approx. 1,000

Northamptonshire





My background

- 1978 – present
- Hospital, social care settings with adults and children
- Manage autism social care services in Northamptonshire
- Part-time lecturer at ACER, University of Birmingham
- Work with Division TEACCH, UNC-Chapel Hill



What is respite care?

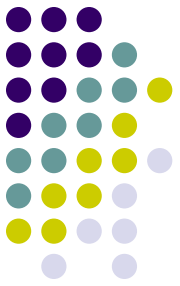
- Service that provides positive, enjoyable opportunities to the disabled young person and their family
- Gives the family a break from caring, chance to relax
- Gives young person time away from family



Historical perspective

- C19 – early C20: institutions and long-stay hospitals
- Post-1945: mostly hospital-based support
- 1970s: beginning of ‘social services’ support. First respite care services in community
- 1979: First family-based services
- 1993: First autism-specific respite care service (Northamptonshire)

Respite care – short breaks from providing care



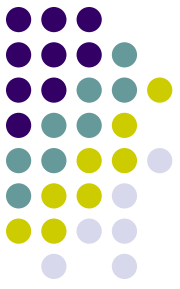
- Benefits to families
- Benefits to children on the autism spectrum
- Benefits to local government and the state



Benefits to families

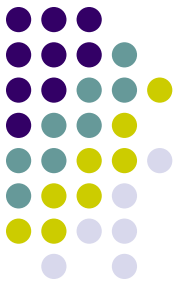
- Effective respite care reduces family stress and help families stay together
- Provides support – families that include young people on the autism spectrum are at risk of limited support from family, friends and neighbours
- Allows time for activities that cannot be undertaken when the young person on the autism spectrum is at home
- Benefits for siblings – parental attention and time, chance for social life, break from caring role

Benefits to the young person on the autism spectrum



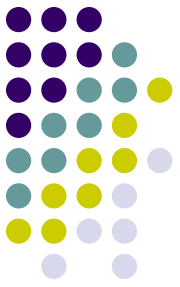
- Positive experiences
- Social and socio-educational opportunities
- Steps towards greater independence and adulthood

Benefits to local government and the state



- Can help families continue caring for child on the autism spectrum
 - Reduction in family breakdowns / out-of-home placements
 - Financially, ethically & practically more effective
- When child remains in local community, easier to plan for adulthood
- Financial saving: current UK services save govt £35.5m per year across social care, health and education budgets (*Action for Children 2009*)

Problems in respite care services regarding young people on the autism spectrum



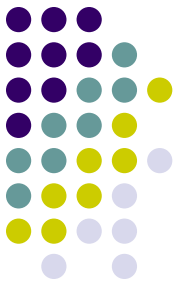
- **Young people with highest levels of dependence / challenging behaviour:** least likely to access services
- Lack of ‘autism-friendly’ services
- Problems with:
 - exclusion
 - service-user mix
 - activities
 - staff skills and understanding
 - environmental factors



Autism – a separate case?

- Evidence from education – young people on the autism spectrum benefit from specialist adapted approaches
 - teaching
 - environment
 - communication
- Norms appropriate for children with special needs – may not apply to them (*Jordan & Jones, 1997*)
- **Equally valid regarding social care provision**

What did we do in Northamptonshire?



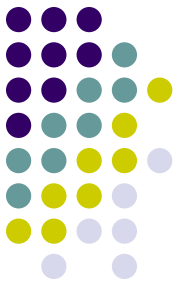
- Worked together – local government, NGOs, families, teachers, social workers, speech therapists
- Consistent use of evidence-based approaches across settings – TEACCH, PECS, Social Stories
- Continuum of support



The Northamptonshire approach to providing services for people with ASD

- From 1990 - multidisciplinary strategy & approach, underpinned by use of **TEACCH**
- Integrated network of services, in
 - Education
 - Children's Services
 - Adult Services
 - State and voluntary sectors

Continuum of support



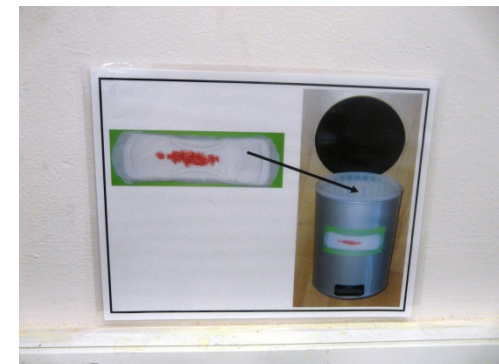
- Autism Family Advisory Team – *empowering families, teaching skills*
- 82 Northampton Road – *providing breaks from caring*
- Arnold House – *home while it is needed*



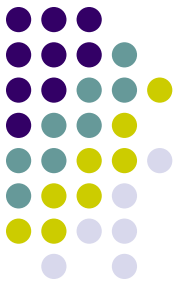
Autism Family Advisory Team



- Empower families to understand autism and use effective approaches
- Range of interventions – surgeries > direct work in real time
- Assess > develop resources > model > teach family > support



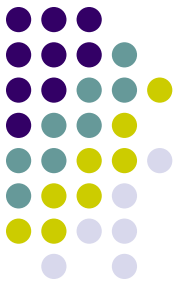
Intermediate stay home – Arnold House



- 6- bed home for young people aged 8-18
- Home while needed (1 month – indefinite stay)
- Focus of work –
 - development of independent living skills
 - positive behavioural support
 - positive family relationships



Residential respite care – 82 Northampton Road



- 6-bed home, providing residential breaks to over 40 young people (5-18 yrs), open 360 nights per year
- Breaks pre-booked – level of care dependent on family's assessed level of need, young person's age/needs/wishes & bed availability

Making respite care work: factors associated positively with high quality respite services



- Physical environment
- Consistency
- Use of ASD- appropriate approaches
- Staff attributes + understanding of autism
- Individualisation
- Activities available/accessing the community
- Grouping of children

(Preece 2009)

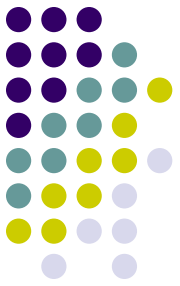
1. Physical environment



- Strengthened glass
- External security
- Lighting and water
- Flooring and walls
- Space – clear purpose, labelled
- Transition area
- Gardens + activities
- Storage
- Furniture

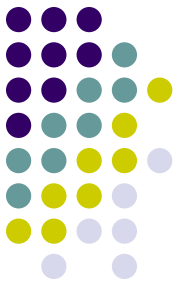


2. Consistency

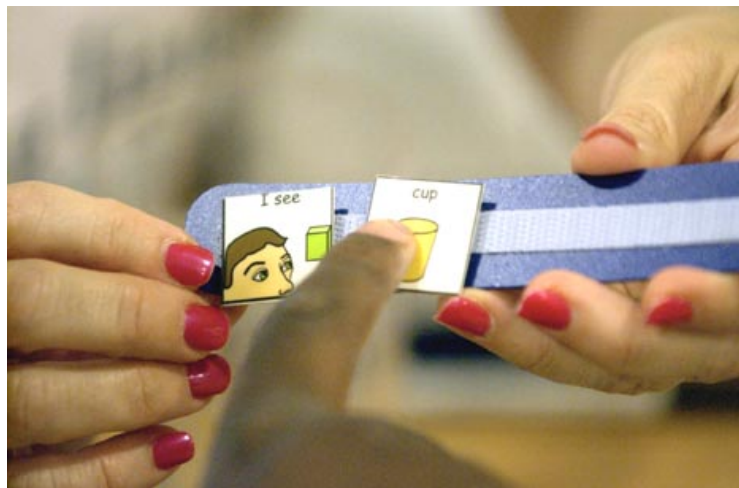


- Consistent use of same structure, approaches + positive routines between school, respite and home settings
- Identified 'key worker'
- Regular liaison and meetings

3. Use of ASD-appropriate approaches



- TEACCH
- PECS (Picture Exchange Communication System)
- Social Stories



4. Staff attributes and understanding of autism



- Imaginative, flexible
- Able to adapt communicative style
- Able to adapt social interactive style
- Good team-workers
- Humility
- Training in autism, TEACCH, PECS, Social Stories, low arousal, behavioural intervention

FROM - OLGA BOGDANSKIHA - SENSORY PERCEPTUAL
ISSUES IN AUTISM & ASPERGER SYNDROME (2003),
Appendix 3

Photocopiable Rainbow and Table

NAMING - ROBERT JONES
D.O.B. 15.3.97.
DATE OF ASSESSMENT - MARCH 15, 2008.

V	H	T	S	P	Y	G
1						
2						
3						
4						
5						
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7						
8						
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VESTIBULAR
TASTE
TOUCH
HEARING
VISION
PROPRICEPTION

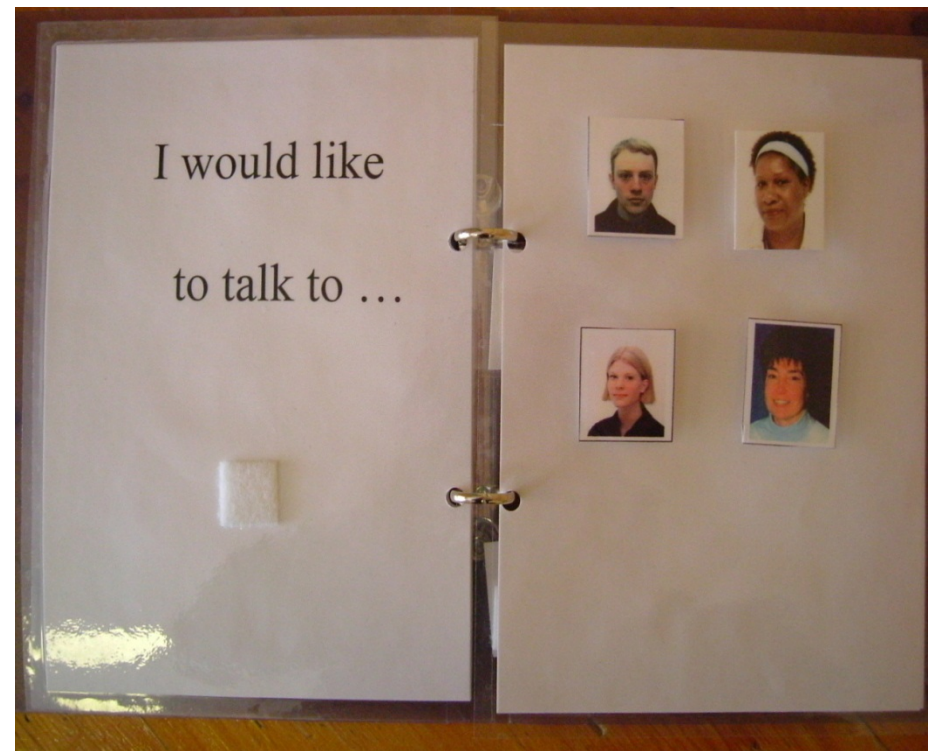
- ### Three-month Assessment Form
- Initial Responses**
1. Did the child come into the unit calmly?
- | Date | 8/5 | 8/4 | 12/5 | 10/4 | 7/8 | 8/4 | 5/8 | 3/8 | 10/6 | 4/6 | 2/6 | 9/7 | 10/4 |
|----------|--------------------------------------|---|--|---|-------------------------|------------------------|--------------------------|-----|------|-----|-----|-----|------|
| Comments | Yes,
was
downcast
at first. | Yes.
He
seemed
to be
looking
forward
to coming
here. | Yes.
He
happy
pleased
to be
here. | Yes.
Seemed
happy
mum
replied
he was
excited. | Yes.
Very
Excited | No.
Quite
happy. | Yes.
Seemed
happy. | | | | | | |
2. Did the child respond positively to staff?
- | Date | 8/5 | 8/4 | 12/5 | 10/4 | 7/8 | 8/4 | 5/8 | 3/8 | 10/6 | 4/6 | 2/6 | 9/7 | 10/4 |
|----------|--|---|--|--|-------------------------------|--------------------------------|--|-----|------|-----|-----|-----|------|
| Comments | Yes,
was
happy
to talk
about
things
appropriately. | Yes.
Asked
him
to
talk
about
things
appropriately. | Yes.
Said
hello
to
everyone
OK. | Yes.
Responded
to all
staff
members. | Yes.
Cheerful
at times. | No.
Has been
quite good. | Yes.
Although
did not
listen
at times. | | | | | | |
3. Did the child respond positively to the other children?
- | Date | 8/5 | 8/4 | 12/5 | 10/4 | 7/8 | 8/4 | 5/8 | 3/8 | 10/6 | 4/6 | 2/6 | 9/7 | 10/4 |
|----------|---|---|---|---|---|---|--|-----|------|-----|-----|-----|------|
| Comments | Yes.
Did not
really
speak
with
them &
them.
Shy. | Yes.
Was
happy
to sit
with
them &
talk.
Hello. | Yes.
Spoke
to them
often
naturally. | Yes.
Liked
seeing
each
other
at times.

Physician
with another
client. | Yes.
Copied
them
out
times. | No.
Not talking
and
not
friendly. | Yes.
But did
get a
little
excited
by one
child
and
chase
him. | | | | | | |
- 1

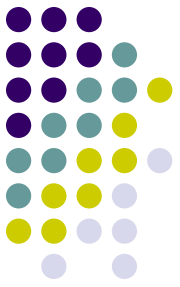


Individualised supports

- All young people have individualised programmes & schedules to meet their individual needs
- Individualised communication systems – from objects to written



6. Activities and accessing the community



- Wide range of activities available
 - in the respite home
 - in the community



Individualised activities

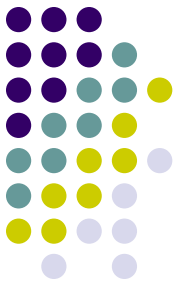
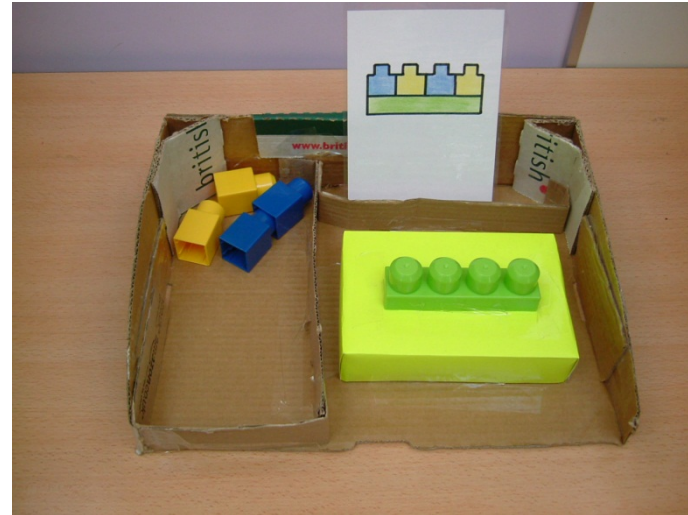


- Ensure young people's activities are built around their interests, strengths and sensory profile

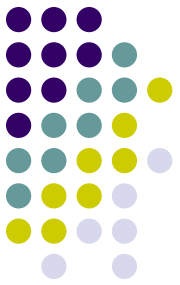


Structuring activities

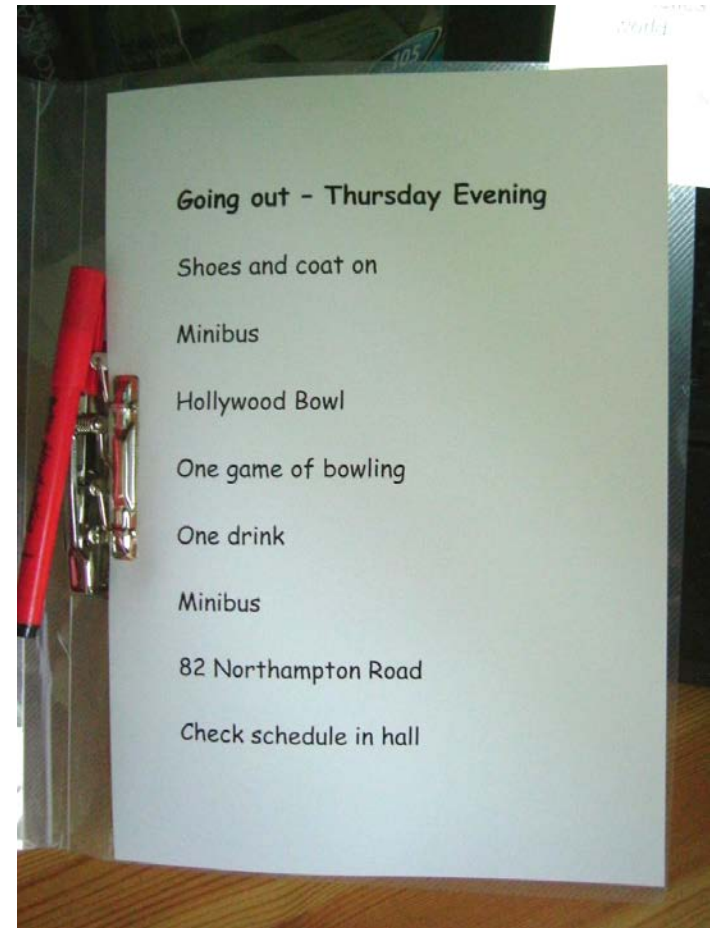
- Structure up activities to provide
 - organisation
 - instruction
 - clarity



Taking structure into the community



- Ensuring that appropriate structure is taken out and about
- Minimises children's anxieties in a confusing world
- Clarify finish



7. Grouping the young people



- Young people use the service with
 - others they can tolerate
 - common interests + skills
- Enables group activities to occur
- Fun